



Dear Sir/Madam,

We are writing regarding the genome project, The Brazilian Initiative on Precision Medicine (BIPMed). In order to ensure privacy of sensitive genetic information, we are seeking clarification on your data sharing policies.

We note that your project involves data sharing with registered users, with tiered access to data for secondary use. This will include tier 2 data that is de-identified and thus presents the possibility of re-identification of participants. We thus seek clarification on who may register for data access, if this includes private companies, insurance companies, law enforcement or immigration services. The consent form offers the opportunity to permit access to public databases, but it does not explicitly state who indeed may have access, and if it is just restricted to public research institutions.

We further seek clarification on exactly what data is shared, and what privacy protections are in place to prevent access to identifiable genetic information in the hands of the project and third parties, by law enforcement and immigration services, including what policies are in place to prevent data breaches by your organisation or third party collaborators. Further, we seek clarification on whether such data is sold to third party companies.

We note that the data sharing agreement includes a confidentiality clause, and request access to this agreement, and what processes are in place to ensure that such clauses are adhered to.

We could not find any information on what occurs to data following withdrawal of participants and whether data is retained or deleted. The consent form refers to removal of the blood samples, but there no reference to data. We thus seek information about what happens to participant data if they withdraw from the project, and if such data will continue to be shared with third parties upon request.

The information that is provided, or not provided to us, will be shared with the public in order to promote transparency and to inform on the privacy implications of growing genetic databases. We thus thank you for any information that you can share with us to facilitate this process.

Yours sincerely,

Dr [REDACTED]

Policy Officer

Email: [REDACTED]